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ABSTRACT

Lifestyles of parents of autistic children were assessed through volunteer participation in a telephone survey, and comparisons were made between responses of mothers (N=21) and fathers (N=12). Almost half of the fathers contacted did not answer the survey. The study examined a variety of therapy-related and demographic variables, including parental optimism at diagnosis, parental optimism during treatment, financial burdens associated with therapy, and stress levels of individuals and their spouses. The impact of an autistic child on participants' marriages was also examined, including the question of how much quality time participants were able to spend alone or with their spouse. Most respondents felt that having an autistic child had added stress to their marriages, with 31 percent reporting an adverse impact on their marriage and 34 percent reporting that they felt their marriage had been strengthened by their experience. Thirty-nine percent of the families pay the total cost of behavioral treatment without any assistance. Mothers spent significantly more time supervising their children's therapy; few other gender differences were found. Self-selection of participants may have favored inclusion of more involved fathers, reducing the opportunity to assess parental gender differences in attitudes and stress levels. (PB)

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ED 390 236

Parental Perceptions of the Lifestyle Changes Associated With Having an Autistic Child: A Gender Comparison

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Abstract

Lifestyles of parents of autistic children were assessed through volunteer participation in a phone survey. A comparison was made between mothers and fathers of autistic children. Group means were calculated for a variety of demographic, and therapy related variables. T-tests were performed on measures of parental optimism at diagnosis, parental optimism during treatment, the financial burden associated with therapy, and the stress levels of the individuals and their spouses. Mothers spent significantly more time overseeing their children's therapy; few additional sex differences were found. Self-selection of participants may have favored inclusion of more highly participative fathers. This may have reduced the opportunity to observe parental sex differences in attitude and stress level.

Parental Perceptions of the Lifestyle Changes

Associated with Having an Autistic Child:

a Gender Comparison

Autism is a severely incapacitating lifelong developmental disability that typically appears during the first three years of life. It is the result of a neurological disorder that affects the functioning of the brain. Autism and its behavioral symptoms occur in approximately fifteen out of every 10,000 birth, and boys are four times more likely to have autism than girls. It is found throughout the world in families of all ethnic, racial, and socioeconomic backgrounds. Some symptoms of autism include disturbances in social and language skills, abnormal responses to sensations, and abnormal ways of relating to people, objects and events(The Advocate, 1994).

Raising a child with a significant disability is extraordinarily stressful(Gill & Harris, 1991). Autism has been found by several researchers to be more stressful for parents than any other childhood disorder, including mental retardation and chronic physical illness(Bristol, 1984; Cummings, Bayley, & Rie, 1966; Holroyd & McArthur, 1976). The chronicity of the disorder can leave parents exhausted,

pessimistic, and at risk for burnout(Factor, Perry, & Freeman, 1990). One reason for this parental reaction is that many parents never get a break from their child because it is often extremely difficult to obtain suitable child care arrangements(Factor, Perry, & Freeman, 1990). Mothers report more stress than the fathers when raising a child with autism(DeMyer, 1979, Holroyd, 1974).

In the following study, the researchers completed a series of phone surveys asking the mothers and fathers of autistic children to estimate their level of optimism about their child eventually developing the skills necessary to live independently as an adult both when diagnosed and after treatment, the time they spend overseeing their autistic child's therapy, the financial burden of treatment, and the quality time they were able to spend with themselves as well as with their spouse. They were also asked to estimate the level of stress for their partners, and to describe how having an autistic child has affected their marriage. The researchers hypothesized that there would be a significant difference between men and women in responding to their questions.

Method

Subjects

The participants were 33 parents of autistic children, 21 women and 12 men from the Montgomery County Region of Pennsylvania. The names of subjects were provided by The Autism/PDD Support Group of Montgomery County. Forty percent of the mothers and 100% of the fathers were employed outside of the home. The average number of hours per week that the women worked outside of the home was 11.75. The average number of hours per week the men worked outside of the home was 46.0. In addition, seventy-eight percent of the families had one or more child other than the child with autism. Twenty-two percent of the families had only one child (the autistic child). The average age of the autistic child when he/she was diagnosed was 3.0 years. The average current age of the autistic children was 6.98 years. The families were participants in a number of different therapy programs, including Lovaas Behavioral Therapy, Partners in Therapy, TEACH, etc.

Procedure

A 13-item self report questionnaire was administered via telephone to assess the lifestyles of parents with autistic children. The survey was kept short to minimize inconvenience to participants. Subjects were assured confidentiality, and were informed that results would be based on group averages only.

Results

Thirty-nine percent of the families surveyed pay the total cost of behavioral treatment without any assistance. For the rest of the families, the state contributes 27%, the school districts and parents contribute 13% and insurance companies pay 8% of the treatment expense.

Men spend significantly less time than women in overseeing their autistic child's therapy (men:$x=3.23$ hours/week, $s.d=2.68$ and women: $x=17.95$ hours/week, $s.d.=30.30$, $N=22$; $t(8.50)$, $df=20$, $p<.001$). No fathers serve as a formal therapist in the behavioral treatment of their autistic child. Forty percent of the mothers responding to this item serve as formal therapists, for a mean of 9.5 hours per week.

The average number of hours spent alone per week was 8.03 for the women and 3.63 for the men, yielding no significant difference, $t(1.76)$, $df=30$, $p>.05$. The average time spouses estimate they spend together as a couple was 7.05 hours per week.

Fifty-five percent of the sample believed that having an autistic child has added more stress to their marriage; 31% of participants reported that having an autistic child had adversely affected their marriage, 34% said they feel having an autistic child has strengthened the marriage, and 24% said they feel that having an autistic child has not affected their marriage at all.

There was no significant difference between men and women in how optimistic they were about their autistic child developing the skills needed to live independently as an adult, either before treatment, ($t(1.28)$, $df=29$, $p>.05$) or after behavioral treatment

(t(.07), df=28, p>.05). No significant differences were found between men and women in how they perceived the financial cost of having an autistic child (t(.19), df=25, p>.05). Also, no significant gender differences were found when maternal and paternal responses were compared regarding the perception of daily stress experienced by each individual and the perception of stress as rated by their partners.

Discussion

In this sample, only 39% of the parents pay fully for all the costs associated with therapy. This could be due to the fact that the local school systems have been compelled to fund more programs involving autistic children,. in response to advocacy efforts facilitated by an area support group for parents with autistic children. Increasing numbers of diagnosed children, and better organizational efforts on the part of parents have put pressure on area school districts. The state has also increased funding in recent years.

There was a significant difference between the amount of time that fathers dedicate to overseeing their autistic children and the amount of time that mothers dedicate. This is consistent with the parents' differential employment outside the home, and with conventional gender roles.

It was also striking that almost half the fathers contacted did not answer the survey. The lower rate of paternal response than maternal response (over 90%) to the survey was congruent with the hypothesized gender difference in parental treatment involvement. As one father surveyed put it, "my wife deals with everything that is associated with our autistic child. If you have any questions, talk to her."

Only 40% of the mothers and 0% of the fathers serve as formal therapists for their children. This is probably due to time constraints and the fact that the child responds differently to the parent as a therapist than to a stranger as a therapist. In one

case, a mother stated that she formally served as a therapist, but found her child would not concentrate and would just want to be hugged and held instead of doing the drills.

The results showed no significant difference between mothers' and fathers' level of optimism, either at the time of initial diagnosis of autism or during their child's treatment. Possibly the parents have had considerable mutual influence on one another's outlook for their child, and have come to share a common view of their child's future.

The results show that almost half of the couples interviewed believed that having an autistic child has added stress to their marriage. Nearly a third have found the stress to be extremely taxing. In one case, a mother responded that because her husband didn't understand and denied the autism, he left the marriage. For those who were very adversely affected by the stress on their marriage, the constant demands made by their autistic child seemed to be most problemmatic. However, many respondents stated that their marriages had been strengthened by the stress of having an autistic child. In these instances, partners seem to have learned to work together to overcome the challenges; the shared burdens seem to have facilitated greater sharing and intimacy in the marriage.

The success with which these couples appear to be meeting the myriad challenges of raising an autistic child is striking. The fact that this sample was drawn from members of a local support organization may have contributed to their effectiveness in managing stress. A future study might compare the responses of

parents who are not involved in such support groups with those from the current sample, in order to investigate whether support group membership confers advantages.

Mother Father

1. What is the age of your autistic child?_____
   At what age was he/she diagnosed?_____

In Questions 2 and 3, rate your level of optimism/pessimism on a scale of 1-4, where 1 is extremely pessimistic and 4 is extremely optimistic.

[_____]

EXTREMELY PESSIMISTIC	RATHER PESSIMISTIC	RATHER OPTIMISTIC	EXTREMELY OPTIMISTIC
1	2	3	4

2. When your child your child was diagnosed, were you optimistic about his/her chances of developing the skills needed to live independently as an adult?_____

3. How optimistic are you about his/her having the skills to live independently following the behavioral treatment program developed by lovaas?_____

4. Do you have any other children? A. Yes B. NO
   If yes, how old are they?_____

5. Are you employed outside of your home? A. Yes B. No
   If yes, how many hours per week do you work?_____

6. Approximately what percentage of behavioral treatment expenses do you pay?_____
   Insurance pay?_____
   School District pay?_____

7. On a scale of 1-10, where 10 is extremely high, how much of a financial burden is this for you?_____

8. Approximately how many hours per week do you spend overseeing your autistic child's therapy?_____
   (organizing, scheduling)

9. Do you formally serve as one of your child's behavioral therapist? A. yes B. no
   If yes, how many hours per week?_____

Mother Father

10. On a scale of 1-10, where 10 is high, how would you rate your daily stress level at home?_____
Your partners stress level?_____

11. How many hours do you get to spend alone per week?_____
(alone, leisurely, independent)

12. How many hours do you spend alone with your spouse per week?_____

13. How do you feel having an autistic child has affected your marriage?_____

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